

## A. General Information

**Project Title:** Collaborative Approach to Intensive ABA Service Provision for Children with Autism

**Project Working Title:** Intensive Autism Intervention

**Agencies Involved:** Mercy Service Club Autism Center, Dubuque Community School District, University of Iowa Autism Center, Hill & Dales, Child Health Specialty Clinics (CHSC), and Department of Human Services

**Prepared by:** Mercy Autism Center Staff and University of Iowa Autism Center Staff

**Date Prepared:** September 13, 2012

List of stakeholders who may be contacted for information regarding the project.

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## **A. Project Purpose**

### **1. Autism Services in Iowa**

Research-based interventions that are based on the principles of Applied Behavior Analysis (ABA) have demonstrated consistent, lifelong improvement for individuals on the autism spectrum. The National Autism Center has recommended that intensive, early delivery of ABA methodology-based interventions occur immediately upon diagnosis, and be provided for a minimum of 25 hours per week per child ([www.nationalautismcenter.org](http://www.nationalautismcenter.org)). The Centers for Disease Control recently reported data that indicates 1 in 88 children are diagnosed with an Autism Spectrum Disorder in the U.S., which means that strategies for providing the research-based intensive intervention across all environments is critically needed.

Dubuque does not currently offer programming for children with Autism that uses Applied Behavior Analysis methodology. Board Certified Behavior Analysts (BCBA) are one of the few professionals qualified to develop, monitor, treat implement, and supervise these treatments according to research and insurance law. While the Dubuque Community School District (DCSD) and Keystone AEA provide Early Childhood Intervention Services to the best of their ability, they do not have the financial funding to hire a BCBA nor bill for ABA services.

The Mercy Service Club Autism Center provides therapy and services for individuals with Autism and Autism Spectrum Disorders. Staff at the Autism Center have a combined 33 years of education and experience in working with individuals with ASD. Therapy and support provided by the skilled therapists and staff at the Mercy Autism Center has made an impact on the lives of children and adults with ASD in Dubuque. The Autism Center provides diagnostic evaluations, speech, occupational, and behavioral therapy, social skill groups and eating therapy. The staff also provides information, training and consultation for agencies and school systems throughout the tri-state area on autism interventions and treatment.

The Mercy Autism Center is in its third year of operation. Since July of 2010, the Autism Center has completed 97 diagnostic assessments. Collaboration with the University of Iowa CYC-I program has provided quick, easy access to necessary medical management. Any child referred for diagnostic evaluation receives recommendations for therapy, medical tests, educational formats and services, behavior interventions, and family support contacts. These recommendations can provide a path to answers for the family.

State legislators and the Director of the Department of Human Services, Charles Palmer, have requested that the Mercy Autism Center staff create a collaborative Autism Pilot Program that partners with community entities including DCSD, service agencies and DHS to provide a replicable model of intensive services.

A collaborative, family-driven approach to providing the needed intensive interventions that include social service agencies, families, and qualified professionals can be created in an inclusive preschool/school setting. This format requires supervision by a BCBA or trained behavioral psychologist, training of preschool/school staff, family and agency staff in basic interventions, data collection and review to ensure appropriate programming and progress, as well as use of focused curriculum to teach needed skills in all areas. Utilization of this collaborative approach begins with a child find process to ensure early diagnosis and intervention. Collaboration that involves crisis planning is necessary to ensure continued learning and progress and maintain individuals within their community.

## **2. Project Objectives**

1. Train medical professionals, caregivers, preschool/school staff, and early childhood professionals throughout Dubuque County to identify early signs and symptoms for referral for team evaluation and diagnosis.
2. Design and implement Family Navigator support upon diagnosis of ASD to provide assistance to families seeking resources and coordinate care from service providers.
3. Create a demonstration site for providing intensive ABA interventions to children with Autism (ages 3-8) using the STAR (Strategies for Teaching based on Autism Research) curriculum in an inclusive preschool and/or school setting with collaboration of preschool/school staff, therapy staff, BCBA, and service agencies.
4. Provide research-based interventions to teach skills determined through assessment and consistent data collection.
5. Improve communication, readiness skills and social interactions for children with Autism participating in the program.
6. Train preschool/school, family, all levels of medical professionals, employers and all community-based service staff who support children with autism in basic evidence-based treatments to promote respect of individuals, consistency in response and teaching of appropriate behavior.
7. Design and implement transition assistance and crisis prevention/intervention plans to avoid out of home placements, hospitalizations, and family stressors. This will require training and clinical consultation regarding function-based behavioral assessment and treatment.
8. Provide systematic assessment of the implementation of ABA-based instruction and the development of communication, play, social skills, pre-academic and adaptive behavior skills for the children who participate in the ABA Demonstration Site.
9. Develop a system of sustainability to provide research-based services and interventions for children with autism that identifies alternative funding streams for the future.

### 3. Core Project Impact

The above community collaborators are all charged with the care of individuals with special needs including those with autism spectrum disorders. All collaborators also spend time and money to ensure that all staff are providing research-based treatments to individuals with ASD. This pilot program will impact all collaborators by increasing their ability to provide research-based treatments and enable them to work together to improve the lives of those with ASD and their families. It will reduce or eliminate duplication of services and funding by pulling all service providers into a common plan.

The Autism Pilot project will use specific outcome measures in each area of the project. Outcomes will be measured through data collection relevant to the specific area. Child outcomes will include reductions in challenging behavior and increases in social, communication, play, pre-academic/academic, and adaptive skills. In addition, we will assess variables related to access to services. For example, the Family Navigator will be responsible for collecting data on the number of families served, number of recommended services/therapies that families access, etc. Specific outcome measures will be finalized at the time of project funding and with collaboration of community stakeholders and fiscal representatives.

### 4. Partnership with the University of Iowa Autism Center

The University of Iowa Children's Hospital Autism Center will collaborate with the Mercy Autism Center to provide three main functions for the pilot project:

1. **Training** to build and maintain local capacity in diagnosis, functional applied behavior analysis (ABA), and educational interventions.
2. **Consultation** on differential diagnosis and intervention, including behavior analysis, medical management, and educational programming.
3. **Program evaluation** to monitor the implementation of clinical and educational procedures and to measure the effectiveness of the pilot program in producing successful outcomes for children and families.

The UI Autism Center brings together the autism expertise of the Center for Disabilities and Development, Pediatric Psychology, and the Department of Psychiatry, as well as a partnership with the Child Health Specialty Clinic (CHSC) statewide Title V network. The UI Autism Center has the most extensive range of autism expertise in the state and is committed to providing tertiary-level clinical services, training for students and practicing professionals, cutting edge research on causes and interventions for autism spectrum disorders (ASD), and support

for public health initiatives to build an effective system of care to support children with ASD throughout Iowa.

The UI Autism Center is uniquely qualified to partner in this pilot as a result of its experience providing (a) **clinical care** for more than 1,800 ASD patients each year, including over 500 new diagnostic evaluations for ASD; (b) **telehealth consultation** to communities throughout Iowa, including the CYC-I psychiatric consultation program and NIMH and MCH-supported research on providing ABA through telehealth; (c) **training** on conducting functional behavioral assessments and developing behavioral treatments for local school and AEA teams that serve children with challenging behavior and on implementing the STAR (Strategies for Teaching Based on Autism Research) program, which integrates ABA principles into a practical evidence-based curriculum for early childhood and elementary-age children with ASD; and (d) **consultation** to local schools in implementing the STAR program and serving children who exhibit challenging behaviors.

## 5. Constraints

- a. Iowa law does not currently require most public and private health insurance programs to assist in funding the research-based behavioral interventions for individuals with autism. This limits ongoing sustainability of the project and provision of services unless insurance regulations are changed.
- b. Despite the prevalence of autism, there is not widespread recognition of the early signs of autism, the use and practice of research-based interventions, and the impressive outcomes that can be achieved through applied behavior analysis.
- c. Currently, Keystone AEA administration has decided not to participate in this pilot, so it is unclear how their therapy services (speech, occupational and IEP oversight) will impact and/or fit within the demonstration site and the participation of DCSD. Family Navigation, Intensive Intervention and Crisis Prevention/Planning may be limited to non-educational agencies.
- d. Implementation of the ABA demonstration site will involve limiting the number of participating children due to the desire to control parameters and to target the age group (3-8 yr) where evidence is the strongest.

## B. Project Description

1. **Early Autism Awareness Training** - Referral process with physicians, parents, educators, preschools, daycare providers, parent education programs for diagnosis

Training regarding signs and symptoms of autism will be provided to medical providers, parents, educators, preschool and daycare staff, parent education program staff, and other caregivers of children ages 3-8. Individuals providing training may include a BCBA, Speech-Language Pathologist, Occupational Therapist or other professional with experience in Autism Spectrum Disorders and have the following skill set:

- a. Certified/licensed individuals with background and experience in autism who demonstrate skills in speaking to large groups, providing information to others in an understandable format.

These trainings will be provided with an emphasis on referral for early diagnosis, importance of research-based interventions and improved outcomes with intensive intervention. Attendees of the training will be better equipped to detect red flags and signs of autism. Trainings will also provide information regarding referral process for diagnosis.

Collaboration with the Autism Center at the University of Iowa Children's Hospital will provide opportunities to access training for specific skills, increase awareness of service providers, and ensure that information is shared with physicians.

2. **Family Navigator** - System of care navigation and coordination for caregivers of individuals with autism to ensure collaboration among all community providers.

An "Autism" Family Navigator will be a qualified professional preferably housed at Community Circle of Care/Child Health Specialty Clinics. This professional will be held to the qualifications and training of other family navigators within Community Circle of Care and Child Health Specialty Clinics and have demonstrated experience in working and/or living with individuals with autism and/or their families. Family Navigators through Child Health Specialty Clinics complete a 40 hour training program prior to working with families.

The Family Navigator's duties will be as follows:

- a. Provide support, empathy, understanding and listening to families throughout process of diagnosis and/or treatment.
- b. Answer basic questions regarding the referral process and diagnostic evaluation.
- c. Aid caregivers in completion of intake packet.
- d. Be available to participate in diagnostic conference post evaluation if necessary.
- e. Coordinate family team meeting upon choice of provider.

- f. Answer questions for families regarding insurance process, program recommendations and other information that will aid in collaborative provision of services for individuals with autism.
  - g. Assist in development of a crisis intervention plan.
  - h. Continue to coordinate team meetings as needed or at a minimum of every 6 months.
  - i. Support collaboration of providers to ensure family-centered wrap around care
  - j. Collect and provide data on family involvement and services
3. **Diagnosis** - Team evaluation with qualified, certified staff utilizing standardized testing and DSM-IV/V criteria for appropriate diagnosis and identification.

Qualified professionals for diagnostic services are as follows:

- a. Medical Provider – Pediatrician, Pediatric ARNP or PA, Pediatric Psychiatrist, Pediatric Psychologist or Behaviorally-certified ARNP trained in administering Autism Diagnostic Observation Schedule (ADOS). Establishes diagnosis with information provided by the ADOS, correlation with current DSM manual and input from autism team.
- b. Behavior Specialist – Board Certified Behavior Analyst (BCBA), Master's degree, advanced training in research-based interventions for autism. Training in administration of ADOS and ADI-R preferred. Completes ADI-R and Vineland Behavior Scale.
- c. Speech-Language Pathologist – ASHA certified, state licensed, advanced training in research-based interventions for autism. Completes appropriate test for specific language deficits such as the PLS-4 or CELF-4.
- d. Occupational Therapist – registered, state licensed, advanced training in research-based interventions for autism. Reviews and scores Sensory Profile.
- e. Consultation services by a licensed psychologist, developmental pediatrician or psychiatrist from the University of Iowa Autism Center.

Upon detection of red flags and signs of autism, parents will be directed to begin the diagnostic process. A physician's order for autism diagnostic evaluation will be sent to a qualified autism clinic. Parents of the child will also be directed to begin the intake packet for the evaluation. Any questions regarding the diagnostic process will be directed to an autism-focused Family Navigator who can assist with understanding the diagnostic process.

Upon receiving an intake packet from a caregiver regarding a desire for autism diagnostic evaluation, the clinic staff will take steps to set up the evaluation appointment. Prior to the appointment date, a Sensory Profile

(part of the intake packet) will be scored and reviewed by a licensed Occupational Therapist. The Behavior Specialist will also conduct a phone interview to complete the Autism Diagnostic Interview – Revised (ADI-R).

On evaluation day, with utilization of a one-way mirror, each qualified medical provider will complete their standardized assessments simultaneously with observation of child and parent responses. Upon completion of the evaluation, the team will review the information and make a diagnosis (if warranted) and recommendations for treatment and/or intervention. Treatment recommendations are given in the areas of therapeutic, family, educational, medical and behavioral recommendations. Whether there is a diagnosis of autism or not, recommendations and “Next Steps” are given to the family based upon input from the evaluation team. This information will be conveyed to caregivers in a family conference approximately one week post evaluation.

If there is a diagnosis of autism, the family navigator may be invited to the conference if needed. If there is not a diagnosis the family navigator will put the family in contact with the appropriate navigator and case management. The family navigator will follow up with family within one week of diagnosis to answer questions and aid in choosing providers and beginning collaboration process.

**4. Caregiver Training** - Training regarding standard, research-based interventions for collaboration among all providers

When parents choose a provider of behavioral services and/or an educational setting, coordination and/or training of direct staff, caregivers, and any service agency staff directly involved with the child will be conducted by the BCBA charged with the child’s behavioral services. The training will incorporate the specific goals and behavior program for that individual. Trained staff will leave with the necessary tools for consistent, accurate implementation of the learning program for that child. This will provide collaboration of all community entities to ensure intensive research-based services are delivered in all environments. It is necessary that the family navigator also understand the program in order to answer questions accurately and support collaboration.

As community providers increase, and support staff change, ongoing training would need to occur. Caregiver training in the pilot project may be limited to the specific individuals supporting the child. Future opportunities to train service providers throughout the community would be beneficial.



5. **Applied Behavior Analysis Demonstration Site** - Demonstration of research-based interventions using applied behavior analysis to implement intensive early intervention services

In support of the research-based interventions, two demonstration sites for intensive applied behavior analysis services will be created within an inclusive preschool/school environment in Dubuque Community School District.

In collaboration with the Iowa City Community School District, the University of Iowa Autism Center is currently implementing three model site classrooms using the STAR curriculum and strategies based on the principles of Applied Behavior Analysis. These sites are closely aligned in format and purpose with this pilot project. Collaboration with the Autism Center at University of Iowa will provide additional data, training, and ability to replicate the pilot systems and processes throughout Iowa.

At the beginning of the pilot program, the UI Autism Center in collaboration with trainers from the STAR program will conduct a 3 day onsite staff training on the implementation of the essential treatment components of the STAR educational curriculum. This will include organization of the classroom/demonstration site, development of efficient schedules, assistance with student assessment, identification of appropriate STAR lessons for children, and hands-on staff training with the implementation of the program with children.

The child's individual program will be created based on recommendations from the evaluation and family choice. The provider of behavior services will provide the BCBA, who will oversee the program, goals and progress. Speech therapy, occupational therapy, physical therapy (if needed), and curriculum will be coordinated throughout the program, utilizing research-based interventions. Each child within the demonstration site will have a one-on-one direct staff throughout the day to assist in implementation of individualized programming.

Individual progress will be monitored by therapists, aides and BCBA weekly and programs will be adjusted as determined by data review. Meetings will occur at a minimum of every other week between direct staff, BCBA and therapists to ensure progress and prevent crisis. Due to constraints listed above, it will be unlikely that children within this demonstration program will be able to utilize speech, occupational, and physical therapy through Keystone Area Education Agency. A therapy service provider will also be chosen by the parents when choosing a provider of behavior services. This may be the same provider.

Direct staff of the private preschool/school environment will have specialized training regarding the child's behavior and learning program. This specialized training will be the responsibility of the chosen BCBA and the staff of the UI Autism Center.

The demonstration project will have space for 10 students age 2-8 with a diagnosis of autism or autism spectrum disorders within the Dubuque Community School District.

6. **Crisis Prevention and Planning** - Planning and behavior consultation to reduce crisis events and avoid out of home placements.

Individuals with an Autism/Autism Spectrum Diagnosis may have periods of crisis that involve significantly aggressive or emotional behaviors that impact their lives at home, community and school. If an individual **involved in the demonstration site** experiences an escalation of challenging behavior, the twice-monthly meeting of the BCBA, direct care staff including educators, family navigator and family will provide the format for determination of strategies or interventions. This may include a referral to physician, another evaluation to determine current needs, increasing respite services or other community options. We expect that regular consultation regarding problem behavior from staff at the UI Autism Center, either through telehealth or through rapid clinic access, will minimize the need for more extensive crisis intervention services. In addition, UI Autism Center staff will provide more advanced training and monitoring for function-based behavioral treatment to enhance staff competencies and further reduce the likelihood of need for out-of-home placement.

An individual with a diagnosis of Autism/Autism Spectrum **who is not involved in the demonstration site** of the pilot project and is experiencing an escalation of challenging behavior(s) may contact the Family Navigator to initiate quick access to support systems. The Family Navigator may identify availability of specific community services including Crisis Prevention services, Crisis Intervention services, and other processes as needed.

Crisis Prevention services may be indicated for a child/family who is experiencing significant challenges, but the child or other family members are not in immediate physical danger. Crisis Prevention services could include referral to local physician, referral to BCBA for Functional Behavior Assessment or Functional Analysis, temporary respite for family, referral to University of Iowa Hospitals/Clinics, Family Team Meeting, or other supports as available. Crisis budget is calculated for 36 events

(Prevention and Intervention) over the 3 year project period; estimation of 9 events per year needing Crisis Prevention services.

Crisis Intervention services may be indicated for a family/child who is experiencing significant challenges that could cause harm to the child or other family members without removal of the child from the home. Crisis Intervention services could include crisis care admission to temporary out-of-home placement, referral to BCBA for Functional Behavior Analysis, interaction with psychiatrist through direct visit or Telehealth, access to medical and social supports and services and other services/supports as needed. Crisis budget is calculated for 36 events (Prevention and Intervention) over the 3 year project period; estimation of 3 events per year needing Crisis Intervention services.

Core Crisis Services currently being discussed and designed through the Mental Health/Disabilities Redesign Task Force will be accessed for critical crisis events.

7. **Program Evaluation** – The UI Autism Center will provide overall program evaluation and data analysis, although the local BCBAs and direct care staff will monitor individual progress weekly and will make modifications in programming if the data suggest the need. Under the supervision of faculty in the UI Children's Hospital, a part-time program assistant/data manager will compile, analyze, and summarize data from all sources in the project to assess project outcomes and identify areas that require enhancement or modification before this intervention model can be implemented in other regions across the state.

As noted in the section on Project Impact, we will assess variables that measure both program fidelity and child-centered outcomes. Because ABA-based programming like STAR relies on frequent data collection and graphing to chart student progress, we will be able to assess each child's increases in social development, communication, pre-academic skills, play, and functional routines. We will also evaluate reduction in problem behavior and increases in rates of task completion. Through observations of project staff during child interactions, we will evaluate staff behaviors to ensure that the program procedures are being implemented with fidelity to the program design. We will also assess variables related to access to services, including the services and therapies that are recommended to families, the number and intensity of services accessed, and parent satisfaction with the services received.

To carry out evaluation of the educational procedures implemented in the demonstration site, the UI Autism Center will provide monthly onsite visits to observe, collect program fidelity data, and provide feedback and consultation on the implementation of the essential components of the STAR program. Program fidelity will be measured using a combination of

indirect and direct behavioral measures. Indirect measures will include rating scales of teacher, parent, and administrator acceptability of the STAR curriculum. Direct measures will include the use of observational rating scales (developed by the authors of the STAR curriculum) used to evaluate: (a) the environmental arrangement of the program (e.g., visual schedules, work areas, and organization of materials), (b) implementation of discrete trial, pivotal response treatment, functional routines, and basic behavioral principles, (c) data collection and visual representation of student progress, and (d) implementation of efficient classroom scheduling. In addition, frequency measures that assess the percentage of treatment steps implemented correctly by educational staff will be collected. Collaboratively, these data will be presented and discussed with program collaborators in mid-year and annual reports with consultation and review by the UI Autism Center.

## **C. Strategic Justification**

### **1. Project Strategic Fit**

The Autism Pilot Project provides the intensive, research-based interventions that increase skill levels for children with Autism. Utilizing methodology that has repeatedly proven to improve lifelong outcomes is consistent with the Department of Human Services goal of independence and quality of life for all individuals with disabilities. Collaboration among community entities facilitates parity in funding of services across environments.

### **2. Project Compliance**

The Autism Pilot Project will comply with all professional standards and policies for each provider's area of focus, and comply with state professional licensing requirements. The pilot project complies with current DHS policies and guidelines as currently written.

## **D. Estimated Project Development Schedule (Major Milestones)**

<b>Event</b>	<b>Date</b>
Event Estimated Date Duration	
Project Mission Approved	Feb 2012 (mtg w Director Palmer)
Project Plan Completed	August 1, 2012

Project Plan Approved	March 2013
Project Execution – Started	
Community Awareness Training	April 2013
Family Navigator	April 2013
Diagnosis	ongoing
Caregiver Training	Upon diagnosis and agreement by family to participate in pilot
ABA Demonstration Site	August 2013
Crisis Prevention and Planning	June 2013
Project Execution – Completed	July 2016
Project Closed Out	December 2016

## E. Financial Estimate

### 1. Economic Justification

Currently, intensive interventions for children with autism are not covered services through private or public health insurance, nor through a Medicaid waiver in Iowa. Children who are diagnosed with autism receive extremely limited services through Early Access (if diagnosed prior to age 3). Instruction through DCSD is provided after the age of 3, if determined qualified by an IEP team. Currently, therapy services (speech, occupational and/or behavioral) are provided by Keystone AEA and are limited to budget, staff parameters and administrative priority. The current system and process does not appear to address the core issues of autism early enough, and with intensity, many children with autism maintain, create, and engage in challenging behaviors which require more staff, more medical services, and more crisis services.

Applied Behavior Analysis, a methodology for teaching and increasing appropriate behaviors, is the only research-based intervention that has proven to provide substantial, documented improvement in language, social interactions and cognitive skills. This improved functioning level translates to decreased needs for funding and support as a teenager and adult. Specific cost benefits can be found in the addendum documents.

Revenues from the project will be used to provide supervision and oversight by a BCBA for interventions, training of community providers, physicians, and general public, caregiver training to promote generalization of skills to all environments, and crisis planning/intervention as needed.

### 2. Estimate of Execution Expenditures and Funding

See attached itemized budget

## **F. Project Risk**

### Budget Risk

1. Proposed budget may not represent actual hours needed by a specific staff person. Budget is based on estimation of hours in each area of project.

### External Dependencies Risk

1. The project is not dependent upon another project. However, continuation and/or replication of project is dependent upon legislation approving an Expanded Autism Insurance Law.

### Management Risk

1. There is no risk to the management capability.

### Mission Critical Risk

1. The current system and processes in place by each community stakeholder will remain as currently organized if the project is not funded or barriers are too numerous to overcome.
2. The current system and processes do not allow for coordination of services and collaboration on intervention techniques between community stakeholders.
3. Community stakeholders will continue to struggle to provide adequate services to individuals with autism without the training and oversight provided by the project.
4. Individuals with autism and their families will continue to struggle to understand processes, procedures and programs that might assist them and their child.
5. Individuals with autism will not receive the research-based intervention that would provide the best possible lifelong outcome.
6. The Department of Human Services and Medicaid will continue to spend increasingly exorbitant funds on providing services to adults with autism who did not receive appropriate teaching and support as a young child.

### Failure Risk

1. Barriers identified may prevent the most critical component (Intensive Intervention) from being provided to children.
2. Funding will not be available for the pilot project.
3. Iowa will not pass an Expanded Autism Insurance Law, which will reduce the ability to provide services beyond the project completion.

### Complexity Risk

1. The project is separated into components to allow for appropriate planning, implementation and data collection. Each component can stand alone; but is a comprehensive system change approach that will improve coordination, collaboration and implementation of research-based services for children with autism.
2. A variety of stakeholders may be providing services to a single child, and coordination of meetings and trainings may be difficult.
3. Billing and funding is shared by multiple entities; coordinating budget data may be difficult.
4. Each stakeholder has different documentation processes; determining precise outcome data may be difficult.